Published in final edited form as:

Arch Phys Med Rehabil. 2019 April ; 100(4): 703–710. doi:10.1016/j.apmr.2018.11.017.

Associations of participation focused strategies and rehabilitation service use with caregiver stress following pediatric critical illness

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Abstract

Objective(s).—Determine the associations between having participation-focused strategies and receiving rehabilitation services in the pediatric intensive care unit (PICU) with caregiver stress over six months post-PICU discharge.

Design.—Sub-study of a data from Wee-Cover, a prospective cohort study.

Setting.—Two PICU sites.

Participants.—Caregivers (N = 168) of children 1-17 years old admitted into a PICU for 48 hours.

Main Outcome Measures.—Data were collected from caregivers at enrollment and 3 and 6 months post-PICU discharge. Caregiver stress was assessed using the Pediatric Inventory for Parents. Having strategies to support their child's participation in home-based activities was assessed using the Participation and Environment Measure (PEM). In PEM, caregivers report on strategies used to support their child's participation in home-based activities. Data were dichotomized (yes, no) to denote having participation-focused strategies and if their child received PICU rehabilitation services. Additional covariates were history of a pre-existing condition, child age, length of PICU stay, and change in functional capacities at PICU discharge.

Results.—History of a pre-existing condition, time, and change in functional capacities significantly predicted caregiver stress frequency and difficulty. The interaction of having strategies-by-rehabilitation-by-time significantly predicted caregiver stress frequency and difficulty.

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Disclosure: The YC-PEM is a measure that was used in this study. YC-PEM is licensed for distribution through CanChild Centre for Childhood Disability Research. M. Khetani shares in revenue from YC-PEM sales.

Conclusion(s).—Results highlight the role of early rehabilitation and the importance of working with caregivers to develop participation-focused strategies to support their child's functioning post-PICU. Families of children with a pre-existing condition or those who experience a decrease in function during a PICU stay are susceptible to higher levels of stress and may be a priority population to target for rehabilitation services.

Keywords

Caregiver stress; strategies; pediatrics; critical care; rehabilitation

Each year, over 230,000 children are admitted into pediatric intensive care units (PICUs).¹ The PICU experience may result in long-term physical, psychological, cognitive, and social consequences for both the child and their family, known as post-intensive care syndrome.² As critical care research moves beyond the outcome of mortality as a measure of care quality, it is important to build a comprehensive understanding of patient and family outcomes.^{3–5} One understudied component is the trajectory of caregiver stress post-PICU discharge.

For caregivers, a PICU admission can be highly distressing and their anxiety can be elevated to near panic levels within days of their child's admission.⁶ Notably, the stress levels for caregivers of critically ill children has been reported at higher levels than previous reports of stress among caregivers of children with other diagnoses, such as cancer.³ High caregiver stress persists for months following their child's discharge from a PICU.⁷ Caregiver stress can negatively impact both their and their children's quality of life.^{8,9} Additionally, it may inhibit their ability to care for their child post discharge, as stress can hinder their ability to comprehend and adhere to the child's treatment plan.^{10,11} It is crucial, therefore, to delineate ways of decreasing caregiver stress in order to optimize care prior to PICU discharge.

Caregiver stress has been associated with feelings of helplessness and low self-efficacy for caring for their child.^{6,12–14} Caregivers are accustomed to being the expert on their child and may feel unsure of how to care for their child who has experienced functional decline,^{13,14} as is the case in up to 80% of children discharged from a PICU.³ Therefore, caregivers who have prioritized goals and an established plan for helping their child resume participation in activities of daily life at home may experience decreased stress when caring for their child post-PICU discharge.

Pediatric rehabilitation services typically incorporate caregivers and begin with an assessment of the child's prior and current level of functioning and family priorities, so that a meaningful care plan can be shaped to achieve these family important goals.¹⁵ Therefore, we hypothesize that caregivers whose children received rehabilitation services in the PICU may experience lower levels of stress following PICU discharge, as compared to those who did not receive rehabilitation services.

Furthermore, caregivers equipped with strategies to facilitate their child's participation in home-based activities (e.g., bedtime routines, meal time)¹⁶ may experience lower levels of stress following PICU discharge, compared to those without participation-focused strategies. A strategy is an action taken to attain a goal.¹⁷ For caregivers of children with functional

needs, participation-focused strategies may be referred to as “accommodations” or “anticipatory planning” to increase their child’s attendance or involvement in valued activities. These strategies involve the caregiver having an understanding of the child’s interests and abilities, as well as the child’s environment, to make meaningful adjustments that increase the child’s success in participating in that activity.¹⁸

While having participation-focused strategies may decrease caregiver stress, it is also possible there would be an interaction between having participation-focused strategies and receiving rehabilitation services. Caregivers whose child received rehabilitation may have developed participation-focused strategies as part of their rehabilitation therapies,^{19,20} resulting in strategies that may be further developed and better suited to support their child post-PICU discharge. However, to our knowledge, no prior studies have explicitly examined the impact of caregivers having participation-focused strategies or their child receiving rehabilitation services while in the PICU with caregiver stress across time.

We hypothesized caregiver stress levels will be lower for those who have strategies to support their child’s participation in daily life activities and for those whose child received rehabilitation services during their PICU admission. Additionally, we hypothesized the relationship between having strategies and caregiver stress may vary according to whether the child has a pre-existing condition and whether the child received PICU rehabilitation services.

The objective of this study is to build clinically relevant knowledge about caregiver stress following their child’s PICU discharge, and evaluate the impact of the modifiable factors of receiving rehabilitation services and equipping caregivers with participation-focused strategies to support their child’s engagement in home-based daily life activities post-PICU. Results may inform tailored approaches to early rehabilitation focused on improving parental self-efficacy to support their child’s participation in home-based activities (e.g., getting clean).

Methods

Population

This sub-study involved secondary analyses of de-identified data from the Wee-Cover study, a multi-centre longitudinal cohort study following 180 caregivers of children aged 1-17 years admitted into a PICU for 48 hours.³ The purpose of the Wee-Cover multi-centre study was to determine the functional recovery of children who survive critical illness for the initial 6 months post-discharge, and to evaluate predictors of unfavorable functional outcome. For the purpose of this sub-study, participants were caregivers (parents or legal guardians) of critically ill children enrolled in the Wee-Cover multi-centre study. Details of sample size calculations and eligibility criteria have been previously published elsewhere.^{3,21} Additionally, participants were excluded if they were missing all 3 waves of data on caregiver stress or participation strategies (n=12). Participants’ demographic characteristics and clinical characteristics were recorded at baseline (see Table 1). An IRB waiver was granted prior to analyses.

Measures

For the following measures, participants were asked to complete questionnaires at study enrollment (during PICU admission), and again at 3 and 6 months following PICU discharge.²² Interviews were conducted during follow-up appointment or by telephone.

Caregiver Stress.—Caregivers completed the Pediatric Inventory for Parents (PIP) to describe the stress they experienced related to caring for their child. The PIP is a validated, participant reported measure that evaluates stress related to caring for a child with an illness, without being disease specific.^{10,23–25} The PIP contains 42 items, and for each item caregivers reported on the frequency of their stress (PIP-F) and perceptions of parenting difficulty resulting from their stress (PIP-D). The PIP items cover four domains: 1) child medical care (e.g., “helping my child with medical procedures”), 2) communication related to and with their child (e.g., “speaking with doctor”), 3) role functioning (e.g., “trying to attend to the needs of other family members”), and 4) emotional functioning (e.g., “learning upsetting news”). Caregivers rated the frequency of the items occurring in the past week and the level of difficulty associated with each item on a 5-point scale (from 1 [not at all] to 5 [extremely]).¹⁰ Summary scores for both PIP-F and for PIP-D are computed to represent caregiver stress frequency and difficulty (range for each domain: 42210) and have demonstrated high internal consistency reliability (α : 0.80–0.96).¹⁰ Frequency and difficulty scores were included as time-varying variables.

Participation Strategies.—The Participation and Environment Measures (PEM)^{26,27} were used to ascertain whether caregivers had participation-focused strategies for home-based activities. The PEM is a parent-reported outcome measure of a child’s participation. As a part of the PEM assessment, caregivers report on the strategies they currently use to facilitate their child’s participation in various activities via open-ended questions.¹⁵ Caregivers completed the PEM at baseline and at 3 and 6 months post-PICU discharge.

Caregiver participation-focused strategies for home-based activities were counted at each observation. A quality control screening was conducted first to exclude cases in which the description did not qualify as a strategy ($n = 114$ strategies),^{17,18} either because the caregiver reported a strategy was needed (e.g., wrote “We haven’t had time to think about this”) or the strategy reported was unclear (e.g., single word answer such as “siblings”). The remaining strategies were then independently screened for inclusion by two research staff prior to main analyses, any discrepancies were settled by majority rule in a meeting joined by a third research. For each observation (baseline, 3 months, 6 months), having a participation-focused strategy for home-based activities was dichotomized as either 0, no strategies, or 1, 1 strategies. All three dichotomous variables of having participation-focused strategies from each observation were included in the analyses.

Rehabilitation Service Use.—PICU rehabilitation service use was gathered prospectively during the child’s PICU stay and dichotomized [yes, no] to indicate whether the child received physical, occupational, or speech therapy during their PICU admission.

Covariates.—We controlled for age, length of PICU stay, and change in functional capacities at PICU discharge. Functional capacities were measured using the Pediatric Overall Performance Category (POPC), a gross measure rating the child from good overall performance [1] to brain death [6].²⁸ A change score was calculated by the difference in pre-PICU POPC score and discharge POPC scores.

Data Analysis

Independent samples t-tests and chi-square analyses were used to compare participant characteristics and service use patterns across participants with a pre-existing condition and previously healthy children.

Generalized Estimation Equation (GEE) models were used to assess the association between caregiver stress and having participation-focused strategies at each time point. GEE is a commonly used analytic approach for longitudinal data, as it can handle unbalanced data to include participants with missing information, allowing maximum use of the data set.²⁹ The dependent variable was caregiver stress frequency for model 1 and caregiver stress difficulty for model 2. Including participation-focused strategies and caregiver stress as time-varying variables provides an overall association between these measures longitudinally.

For both stress frequency and stress difficulty, the models were built over a series of steps.³⁰ The first step included the main effects of caregiver stress, participation-focused strategies, and PICU rehabilitation service use, while controlling for covariates. Once significant main effects are established, the second step is to include two-way interactions (participation strategies-by-rehabilitation use and strategies-by-pre-existing condition) to assess if there are significant interactions, i.e., if the strength of the relationship between participation strategies and caregiver stress differed between children who did and did not receive rehabilitation services or children with and without a pre-existing condition. If interactions are found to be significant, then the third step is to add a three-way interaction to determine if any of the significant two-way interactions changed significantly over time.

Results

There were a total of 168 participants in this study, 119 (70.8%) of whom had a child with a pre-existing condition at PICU admission. The baseline demographics of the study participants are presented in Table 1. Children who were previously healthy (i.e., did not have a pre-existing condition) experienced a greater decline from their baseline function, as measured by POPC, compared to those with a pre-existing condition. Ninety-three (55.4%) participants received rehabilitation services while in the PICU.

Caregiver stress:

Caregivers of children with a pre-existing condition experienced higher stress frequency at 3 and 6 months post discharge, compared to caregivers of previously healthy children (see Table 1). For the entire sample, mean caregiver stress frequency decreased from 134.0 (SD 33.4) at discharge, to 110.5 (SD 33.4) and 101.9 (SD 35.4) at 3 and 6 months post-discharge, respectively. Mean caregiver stress difficulty decreased from 118.6 (SD 30.8) at PICU

discharge, to 98.1 (SD 36.4) and 93.3 (SD 37.7) at 3 and 6 months post-discharge, respectively.

Participation strategies:

Across all three observations, 74.4 – 78.0% of caregivers reported having one or more strategies to support their child's participation in home activities. The mean number of strategies reported across observations was 1.7 - 2.3 with a range of 0 – 17 strategies per caregiver.

Model 1: Caregiver Stress Frequency.—Table 2 presents the model with caregiver stress frequency as the outcome, in three steps.

Step 1 results show significant associations between caregiver stress frequency and a child's history of a pre-existing condition, having participation-focused strategies, time, decrease in functional capacities at PICU discharge, and receiving PICU rehabilitation services.

Step 2 results show a significant two-way interaction of participation-focused strategies-by-PICU rehabilitation ($B: -20.81$; 95% CI: $-35.42 - -6.20$). The interaction of participation-focused strategies-by-history of pre-existing condition was not significant and therefore removed from the model.

Step 3 included a three-way interaction of strategies-by-PICU rehabilitation-by-time to examine the effects of having participation-focused strategies and receiving PICU rehabilitation services over time on caregiver stress frequency. History of a pre-existing condition and a decrease in functional capacities at PICU discharge increased caregiver stress frequency by 15.40 (95% CI: 5.53 – 25.27) and 6.57 (95% CI: 2.23 – 2.11), respectively. Each unit increase of time decreased caregiver stress frequency by -25.66 (95% CI: $-35.44 - -15.88$). The interaction of strategies-by-time was statistically significant and for each unit increase in time, caregiver stress frequency increased by 15.01 (95% CI: 3.37 – 26.65). However, the three-way interaction of strategies-by-PICU rehabilitation-by-time was statistically significant; with each observation, there was a -21.31 (95% CI: $-38.71 - -3.92$) decrease in caregiver stress frequency for those who had participation-focused strategies and received rehabilitation services in the PICU.

Model 2: Caregiver Stress Difficulty.—Table 3 presents the model with caregiver stress difficulty as the outcome, in three steps.

Step 1 results show significant associations between caregiver stress difficulty and a child's history of a pre-existing condition, having participation-focused strategies, and time.

Step 2 results show a significant two-way interaction of participation-focused strategies-by-PICU rehabilitation ($B: -21.79$; 95% CI: $-39.46 - -4.10$). The interaction of participation-focused strategies-by-history of a pre-existing condition was not significant and therefore removed from the model.

Step 3 included a three-way interaction of strategies-by-PICU rehabilitation-by-time to examine the effects of the interaction between having participation-focused strategies and

receiving rehabilitation services over time on caregiver stress difficulty. History of a pre-existing condition and a decrease in functional capacities at PICU discharge increased caregiver stress difficulty by 13.50 (95% CI: 2.01 – 25.00) and 5.10 (95% CI: 0.01 – 10.20), respectively. Each unit increase of time decreased caregiver stress difficulty by –24.43 (95% CI: –35.27 – –13.59). The interaction of participation-focused strategies-by-time was statistically significant and for each unit increase in time, caregiver stress frequency increased by 14.72 (95% CI: 2.81 – 26.64). The three-way interaction of strategies-by-PICU rehabilitation-by-time was statistically significant, whereby at each observation, there was a –24.46 (95% CI: –43.39 – –5.54) decrease in caregiver stress difficulty for those who had participation-focused strategies and received rehabilitation services in the PICU.

Discussion

This study investigated the relationship between caregivers having participation-focused strategies and their child receiving PICU rehabilitation services on caregiver stress for the first six months following the child's discharge. Caregiver stress frequency and difficulty were high through the first six months post-PICU discharge and, despite declining over time, were higher than what has been reported in prior literature on caregiver stress specific to diagnoses such as diabetes,³¹ cancer,³² and sickle cell disease.³³ These results fall in line with prior research demonstrating caregivers experience high levels of stress both during the admission and for several months post-discharge.^{7,34}

Caregivers whose child received rehabilitation services during the PICU stay experienced a significant decline in caregiver stress during the first six months post-PICU discharge. Prior work examining pediatric rehabilitation within the PICU has focused primarily on understanding trends in service use^{1,35} and exploring barriers to and safety of implementing rehabilitation services within the PICU.³⁶ These studies found rehabilitation services are feasible within the PICU, and approximately 50% of the PICU population receives rehabilitation services. To our knowledge, this is the first study to examine the association between receiving early rehabilitation services and caregiver stress in any population. Given the high level of caregiver stress post-PICU and its impact on their child and family,¹¹ these results suggest rehabilitation services in the PICU may be a key aspect of optimal PICU care. Future studies to advance knowledge about the role of rehabilitation should account for variability in PICU rehabilitation service intensity (e.g., frequency, duration) as it links to survivorship outcomes.

While there is a paucity in the literature on the association between strategies and caregiver stress, we hypothesized strategies to promote their child's participation would increase their self-efficacy and confidence in caring for their child and would therefore decrease caregiver stress, based on prior findings that low self-efficacy in caring for their child and feelings of helplessness are directly impact caregiver stress.^{12,37} In contrast to our hypothesis, the main effects of caregivers having participation-focused strategies increased caregiver stress frequency and difficulty. There are a few potential reasons for this finding. First, caregivers already having strategies may be an indicator of their child having functional needs prior to PICU admission, which may exacerbate caregiver stress.¹¹ Alternatively, this finding may be attributed to the quality of strategies described. This alternative reason may be further

supported by the significant interaction we found between having strategies and the child receiving PICU rehabilitation services on decreases in caregiver stress frequency and difficulty for 6 months post-PICU discharge. A typical rehabilitation session involves the therapist working with the caregivers to identify priority areas of need and developing or refining existing strategies to facilitate the child's home participation.^{20,38,39} Therefore, the participation-focused strategies of caregivers whose child received rehabilitation services in the PICU may be of higher quality and would potentially be associated with a greater decrease in their stress related to caring for their child.

Lastly, caregivers of children with a history of a pre-existing condition experienced higher levels of stress compared to caregivers of previously healthy children. This is consistent with prior work examining stress among caregivers of children with a chronic illness. Cousino and Hazen (2013) compared stress levels between caregivers of children with a chronic illness and those of healthy children across 13 studies (weighted effect size = 0.40, range = 0.30-0.88).¹¹ Due to the complexities of caring for children with chronic illnesses,^{11,37} these caregivers may have prior experience facilitating their child's engagement in daily life activities.¹⁷ Caregivers of children with traumatic brain injuries utilize a host of strategies, ranging from using prompts to help their child remember instructions, to modifying the activity itself to make it more achievable, or talking through situations before they occur.¹⁷ Thus, we hypothesized that for caregivers of children with a pre-existing condition, having participation-focused strategies may have a weaker effect on decreasing stress for two reasons. First, they may have pre-existing high levels of caregiving stress. Second, it is common for caregivers of children with pre-existing conditions to already be employing multiple strategies to promote participation¹⁸ and thus they may have described participation-focused strategies that no longer apply to their child's new functional needs.

We did not find that history of a pre-existing condition modified the relationship between having participation-focused strategies and stress, suggesting that the impact of having participation-focused strategies on caregiver stress does not vary by the child's pre-PICU health. This finding may be due to variability within the "prior health-condition" subgroup. While prior studies have examined the PICU population as a whole⁴⁰ or by subgroups (i.e., chronic illness, previously healthy/admitted for traumatic injury),⁴¹⁻⁴⁴ future work may benefit from a more detailed cohort classification,⁴ i.e., clearly defining chronic versus complex chronic illnesses^{42,45} and long-stay patients.⁴⁶

Limitations

There are a few limitations to this study. First, rehabilitation service use did not capture session frequency, duration, or caregiver reported satisfaction with services, nor include service use following discharge. Future studies would benefit from capturing these data.^{47,48} While there is no prior evidence of caregiver strategies differing by socioeconomic status, there are known social disparities in rehabilitation service use.⁴⁹ Therefore, future studies would benefit from collecting data on socioeconomic status to examine its effect on caregiver strategies and stress. Lastly, factors not assessed in our study, such as family cohesion and caregiver mental health prior to PICU admission,⁵⁰ may also be important predictors of caregiver in future work to advance knowledge in this area.

Conclusion

As research on outcomes of pediatric critical care continues to expand, understanding the influence of the PICU stay on caregivers becomes a crucial component to understanding how we can improve the PICU experience to promote functional recovery and quality life for critically ill children and their families.^{2,4} This study built foundational knowledge regarding the relationship between strategies and PICU rehabilitation services on caregiver stress over time. Study results highlight the role of early rehabilitation during a PICU admission for ensuring caregivers have strategies to support their child's participation at home by PICU discharge. Families of children with a pre-existing condition or those who experience a decrease in function during a PICU stay are susceptible to higher levels of stress frequency and difficulty, and may be a priority population to target for rehabilitation services during a PICU admission.

Acknowledgements

Research reported in this publication was supported by the Academic Health Sciences AFP Innovation Fund under [ClinicalTrials.gov](https://clinicaltrials.gov) Identifier NCT02148081 (Choong and Fraser) and the National Institutes of Health under Award Number K12 HD05593 (Khetani). We thank Saoirse Cameron for providing oversight of data collection and management, David Pogorzelski for managing the entry of strategy use data reported on in this paper, and Vera Kaelin for critical feedback on earlier drafts. The content is solely the responsibility of the authors and does not necessarily represent the official views of the funding agencies.

Abbreviations:

PICU	pediatric intensive care unit
PIP	Pediatric Inventory for Parents
YC-PEM	The Young Children's Participation and Environment Measure
PEM-CY	The Participation and Environment Measure Children and Youth
POPC	Pediatric Overall Performance Category
GEE	Generalized Estimation Equation

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Table 1.

Demographic characteristics

	Total		Pre-existing condition		Previously healthy		p-value
	N = 168	Mean (SD)	N = 119	Mean (SD)	N = 49	Mean (SD)	
Age	8.3 (5.4)		8.0 (5.3)		9.1 (5.7)		0.260
Male	53.60%		59.70%		38.80%		<0.01
Reason for PICU admission							<0.001
Respiratory failure	38.1%		47.9%		14.3%		
Sepsis	13.7%		13.5%		10.3%		
Surgery	11.9%		14.3%		6.1%		
Trauma	11.3%		2.5%		32.5%		
Neurologic	9.5%		7.6%		14.3%		
Malignancy	5.4%		5.0%		6.1%		
Burns	1.8%		0.0%		6.1%		
Cardiac	0.6%		0.0%		2.0%		
Other	7.7%		9.2%		8.2%		
Length of stay (days)	9.8 (9.3)		10.3 (10.2)		8.7 (6.8)		0.238
Decrease in functional capacities	0.9 (1.1)		0.6 (0.9)		1.9 (1.1)		<0.001
Received rehabilitation services in the PICU	55.4%		52.9%		61.2%		0.394
Discharge destination							<0.001
Home	85.6%		90.8%		73.5%		
Rehab	7.1%		2.5%		18.4%		
Other	7.1%		6.7%		8.2%		
Stress at discharge							
Frequency	134.0 (26.0)		135.2 (27.2)		131.5 (23.0)		0.403
Difficulty	118.6 (30.8)		120.2 (32.2)		115.0 (27.8)		0.313
Stress at 3 months							
Frequency	110.5 (33.4)		115.1 (34.4)		101.4 (29.9)		< 0.05
Difficulty	98.1 (36.4)		102.9 (37.8)		88.7 (32.1)		< 0.05
Stress at 6 months							

	Pre-existing condition		Previously healthy		p-value
	Total N = 168	Mean (SD)	N = 119	Mean (SD)	
Frequency	101.9 (35.4)			91.4 (32.1)	< 0.05
Difficulty	93.3 (37.7)			84.2 (35.5)	0.086
Caregivers with strategies					
At baseline	74.4%		75.6%	71.4%	0.566
At 3 months	78.0%		83.2%	65.3%	<0.01
At 6 months	77.4%		79.8%	71.4%	0.310

Decrease in functional capacities = Pediatric Overall Performance Category change score; Stress = Pediatric Inventory for Parents scores; Caregiver with strategies = Caregiver reported 1 strategy in the Participation and Environment Measures

Table 2.

Model 1: PICU rehabilitation services and participation focused strategies predicting caregiver stress frequency over time

Variables	Step 1			Step 2			Step 3		
	B	95% CI		B	95% CI		B	95% CI	
Intercept	125.75 [*]	112.78, 138.72		116.45 [*]	101.13, 131.78		138.47 [*]	116.65, 160.28	
Age	-0.08	-0.96, 0.81		-0.14	-1.02, 0.75		-0.147	-0.99, 0.70	
History of a pre-existing condition (Previously healthy)	17.24 [*]	7.16, 27.32		16.57 [†]	2.03, 31.11		15.40 ⁺	5.53, 25.27	
Decrease in functional capacities	6.14 ⁺	1.75, 10.52		6.54 ⁺	2.15, 10.93		6.47 ⁺	2.23, 2.11	
Participation strategies (No strategies)	10.62 ⁺	2.77, 18.46		23.24 ⁺	8.23, 38.25		-7.87	-31.71, 15.98	
Length of PICU stay	0.28	-0.20, 0.76		0.29	-0.17, 0.76		0.134	-0.15, 0.78	
PICU rehabilitation services (No rehabilitation in PICU)	-10.13 [†]	-20.19, -0.07		5.10	-9.52, 19.72		-21.66	-51.29, 7.97	
Time	-15.95 [*]	-19.03, -12.87		-15.74 [*]	-18.78, -12.70		-25.66 [*]	-35.44, -15.88	
Strategies X pre-existing condition				-0.56	-16.24, 15.12				
Strategies X PICU rehabilitation				-20.81 ⁺	-35.42, -6.20		21.65	-11.47, 54.77	
Strategies X time							15.01 ⁺	3.37, 26.65	
PICU rehabilitation X time							12.71	-1.85, 27.27	
Strategies X PICU rehabilitation X time							-21.31 [†]	-38.71, -3.92	
QIC	316931.07			309962.07			304157.57		

Parentheses indicate reference category; PICU = Pediatric intensive care unit; Decrease in functional capacities = Pediatric Overall Performance Category change score; Caregiver stress frequency = Pediatric Inventory for Parents Steps = analytic process of building model. Step 1 – assess for significant main effects, Step 2 – assess for significant interactions, Step 3 – assess for significant three-way interaction

[†] = p < 0.05

⁺ = p < 0.01

^{*} = p < 0.001

Table 3.

Model 2: PICU rehabilitation services and participation focused strategies predicting caregiver stress difficulty over time

Variables	Step 1			Step 2			Step 3		
	B	95% CI		B	95% CI		B	95% CI	
Intercept	109.48 [*]	94.79 - 124.18		99.96 [*]	81.98 - 117.94		126.07 [*]	101.48 - 150.67	
Age	-0.19	-1.19 - 0.81		-0.25	-1.25 - 0.75		-0.23	-1.19 - 0.73	
History of a pre-existing condition (Previously healthy)	15.75 ⁺	3.52 - 27.98		14.64	-4.41 - -33.69		13.50 ⁺	2.01 - 25.00	
Decrease in functional capacities	5.0	-0.22 - 10.21		5.33 ⁺	0.13 - 10.53		5.10 ⁺	0.01 - 10.20	
Participation strategies (No strategies)	12.36 ⁺	2.80 - 21.93		25.46 ⁺	8.78 - 42.13		-5.29	-29.74 - 19.17	
Length of PICU stay	0.21	-0.30 - 0.70		0.22	-0.26 - 0.69		0.24	-0.24 - 0.73	
PICU rehabilitation services (No rehabilitation in PICU)	-9.87	-21.02 - 1.29		6.20	-11.44 - 23.84		-33.33	-64.70 - 1.96	
Time	-12.62 [*]	-15.88 - -9.37		-12.43 [*]	-15.66 - -9.21		-24.43 [*]	-35.27 - -13.59	
Strategies X a pre-existing condition				-0.24	-18.71 - 18.23				
Strategies X PICU rehabilitation				-21.79	-39.46 - -4.10		27.38	-9.04 - 63.79	
Strategies X time							14.72 ⁺	2.81 - 26.64	
PICU rehabilitation X time							19.13	2.88 - 35.39	
Strategies X PICU rehabilitation X time							-24.46 ⁺	-43.39 - -5.54	
QIC	399915.38			392392.29			386139.61		

Parentheses indicate reference category; PICU = Pediatric intensive care unit; Decrease in functional capacities = Pediatric Overall Performance Category change score; Caregiver stress difficulty = Pediatric Inventory for Parents; Steps = analytic process of building model: Step 1 – assess for significant main effects, Step 2 – assess for significant interactions, Step 3 – assess for significant three-way interaction

⁺ = p < 0.05

⁺ = p < 0.01

^{*} = p < 0.001